

A Survey of Health Care Providers, Laboratories, and Local Health Departments

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Compliance With California's Non-Name HIV Reporting System: A Survey
of Health Care Providers, Laboratories, and Local Health Departments

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EXECUTIVE SUMMARY

Objectives. The objectives of this study were to: 1) evaluate compliance with California's non-name HIV reporting regulations by health care providers, laboratories, and local health departments; 2) determine factors associated with compliance with the non-name HIV reporting regulations; 3) identify reporting gaps in existing surveillance system; and 4) make recommendations to increase the effectiveness of the non-name based HIV reporting process.

Design. Separate address lists were compiled for local health departments, health care providers, and laboratories. All local health departments and laboratories were mailed surveys, whereas 1,300 health care providers were sampled from available lists. Health care providers were divided into three subgroups: AIDS Drug Assistance Program (ADAP) physicians, California Medical Board physicians, and HIV test counselors. Voluntary responses from participants were entered into Microsoft Access databases. Data analyses were performed using the SAS System.

Results. About 57 percent of health care providers who serve HIV-infected patients report confirmed HIV tests to the local health departments while 81.5 percent of laboratories report all confirmed HIV test results. Non-reporting health care providers cite the lack of HIV patients under their care and the lack of confirmed HIV test results as primary reasons for not reporting. However, 8.5 percent of non-reporting health care providers provided invalid reasons for not reporting. Non-reporting laboratories indicate the lack of resources and other specified reasons are the main reasons for not reporting, but 16.7 percent provided invalid reasons for not reporting. More than 41 percent of health care providers with HIV patients have established a cross-reference system, but developing a cross-reference system is a top request among health care providers seeking training assistance. Approximately 70 percent of laboratories do not report HIV test results electronically, but electronic reporting remains a top training concern among laboratories seeking training assistance. Laboratories take an average of 3.6 days to submit confirmed HIV test results to the local health department. Health care providers take an average of 9.2 days to report to the local health department, which exceeds the 7-day reporting requirement. In particular, ADAP physicians fail to meet the reporting requirement with an average of 12.6 days to report, however, they also handle larger HIV caseloads.

Conclusion. These results show laboratories report HIV cases to the local health department more often than health care providers, affirming the importance of the dual reporting system. Addressing the specified training needs as well as additional training, especially among health care providers, may narrow the reporting gap and help improve overall compliance with the regulations.

INTRODUCTION

Population-based AIDS surveillance in the United States has been in practice since the onset of the AIDS epidemic in 1981. All states report AIDS cases by name to the Centers for Disease Control and Prevention. In the late 1990s, the development of highly effective antiretroviral therapy prolonged the progression of HIV disease to AIDS. Thus, AIDS surveillance alone is insufficient to adequately characterize the HIV/AIDS epidemic. The development of HIV surveillance is necessary to understand trends in HIV/AIDS and to create a more complete picture of the epidemic. As of 2004, all states enforce some level of HIV reporting. Although the majority of states use name-based HIV reporting systems, 13 states, including California, use non-name HIV reporting systems.

California implemented its non-name HIV reporting system on July 1, 2002. The system requires health care providers and HIV test counselors to submit confirmed HIV cases to local health departments (LHDs) using a non-name code in lieu of patient name. The non-name code is comprised of the individual's soundex (a four digit alphanumeric code based on consonants of the last name), date of birth, gender, and the last four digits of the Social Security Number (SSN). Laboratories submit confirmed HIV test results to LHDs using the partial non-name code (soundex, date of birth, and gender). LHDs sort and unduplicate reports by matching them against LHD's HIV/AIDS reporting system and HIV/AIDS case reports from health care providers that have not been entered. Unduplicated HIV cases are sent to the Office of AIDS (OA) using the non-name code.

The effectiveness of the non-name HIV reporting system hinges upon health care providers and laboratories' compliance with regulations to report, as well as their provision of complete, accurate, and timely information on case report forms. A complete and accurate picture of the current HIV/AIDS epidemic can be achieved only through full reporting by all appropriate entities. Compliance levels among health care providers and laboratories can reveal the non-name HIV reporting system's strengths and weaknesses. Thorough evaluation of the system can expose the shortcomings and target training and technical assistance to improve compliance levels.

This study examines the non-name HIV reporting system in California and the level of compliance among the reporting entities: health care providers, laboratories, and LHDs. More specifically, this study examines factors that characterize compliance, such as timeliness, level of reporting, and completeness, as well as satisfaction with other reporting entities, caseload, and the need for further assistance/training. The results of this study will help identify any reporting gaps that may result from underreporting and generate suggestions to increase compliance. Common reasons for not fully complying can be addressed and changes can be made to increase the effectiveness of the system. Refinements made to the system can create a more accurate picture of HIV/AIDS in California and ensure proper allocation of federal, state, and local resources towards care and prevention programs.

METHODS

Separate address lists were compiled to reflect each of the entities involved in the HIV reporting process (i.e., health care providers, laboratories, and LHDs). Health care providers were sampled from three lists. Seven hundred California physicians were randomly sampled from the California Medical Board (CMB) list of all physicians licensed in California to reduce bias from sampling only health care providers with high HIV patient loads. Three hundred physicians were randomly sampled from a list maintained by OA of doctors providing services to patients in the AIDS Drug Assistance Program (ADAP). They were included to ensure a sufficient number of providers with HIV-positive patients. In addition to the physicians, 300 HIV test counselors at confidential sites were randomly sampled from a list maintained by OA because counselors are required to report clients with confirmed confidential HIV results. Survey packets were sent to the laboratory director and staff member responsible for reporting confirmed HIV results from all 285 laboratories on a mailing list maintained by the California Department of Health Services, Laboratory Field Services Branch of laboratories known to perform confirmatory HIV testing. HIV/AIDS surveillance coordinators in all 61 LHDs were sent survey packets. Reminder letters were mailed to potential participants who did not respond within one month. Replacement packets were sent upon request.

In March 2004, potential participants were mailed a cover letter explaining the project, an informed consent form, questionnaire, and the Participant's Bill of Rights. Twenty-five dollar

Border's Bookstore gift cards were given to non-publicly funded respondents when the consent forms were returned with initials and date. Anonymous questionnaires were returned separately from consent forms and entered into Microsoft Access databases. Data analyses were performed using the SAS System (Version 8.2, The SAS Institute, Cary, NC) to generate frequency tables. Questionnaire responses regarding completeness of information and satisfaction were collapsed from five-part scales to three-part scales.

When participants provided an interval for questions asking for a point estimate, the interval's midpoint value was entered. Approximations and greater/lesser than estimations were entered as the given value. When two answers were given for a question requesting one, the first response was entered.

RESULTS

Of the 1,678 deliverable surveys, 447 surveys were returned, yielding an overall response rate of 26.6 percent. Health care providers had an overall response rate of 13.6 percent (145/1,070). Among health care providers, HIV test counselors had the highest response rate with 33/172 (19.2 percent), while ADAP physicians returned 41/278 (14.7 percent) questionnaires and CMB physicians returned 71/620 (11.5 percent). Thirty-eight LHD questionnaires were completed (63.3 percent); one was returned to sender. Two hundred fifty-three of the 1,931 surveys were returned to sender, resulting in a return to sender rate of 13.1 percent. HIV counselors had the highest return to sender rate of 42.7 percent.

One hundred nineteen of the potential 548 laboratory questionnaires (21.7 percent) were completed. Both laboratory directors and staff members from 16 facilities submitted consent forms, while 80 laboratories enrolled one participant and another 176 laboratories submitted no consent forms. Table 1 summarizes the response rate among each sampled group.

Table 1. Response Rate by Reporting Group.

Reporting type	Number of Questionnaires Sent	Potential Participants (excluding return to senders)	Return to Sender Rate (%)	Number of Questionnaires Returned	Response Rate (%)
LHDs	61	60	1.6	38	63.3
Laboratories	570	548	3.9	119	21.7
Health care providers	1,300	1,070	17.6	145	13.6
ADAP	300	278	7.3	41	14.7
CMB	700	620	11.4	71	11.5
HIV counselors	300	172	42.7	33	19.2

Reporting Practices Among Health Care Providers

Of the 145 participating health care providers, 74 (51 percent) have had HIV patients under their care since July 1, 2002. ADAP physicians accounted for 45.6 percent of the health care providers with HIV patients, while HIV test counselors and CMB physicians each accounted for 27 percent. Forty-two of the 74 health care providers with HIV patients (56.8 percent) report confirmed HIV cases to LHDs. Forty-three percent of the respondents do not report when they have HIV patients. Eighty-five percent of CMB physicians with HIV patients do not report to LHDs but 58.8 percent of those that do not report cite they did not receive any confirmed HIV test results from laboratories.

Health care providers and LHDs disagree on how often health care providers submit data elements on HIV/AIDS confidential case report forms. The majority of health care providers with HIV patients claim to report all data elements, except medical record number, on case report forms more than half of the time. The exact proportion of health care providers submitting information more than half of the time varies by data element from as low as 24 percent (medical record number) to as high as 57 percent (gender). Yet a large number of LHDs report receiving certain data elements less than half of the time. For example, 47 percent of health care providers report submitting exposure/risk information more than half of the time, but only 11 percent of LHDs report receiving it more than half of the time. Likewise, 39 percent of health care providers claim to report the last four digits of the SSN more than half of the time; 21 percent of LHDs report receiving such data more than half of the time. Table 2 summarizes these results.

When reporting to the laboratories, health care providers and laboratories agree health care providers generally submit all data elements more than half of the time. A higher proportion of health care providers with HIV patients claim to report all data elements more than half of the time than those without HIV patients. Data elements are submitted by as little as 39 percent (medical record number) to as much as 63 percent (date specimen was collected) of the health care providers without patients most of the time, while data elements are included by as little as 41 percent (medical record number) to as much as 81 percent (name of provider) of the health care providers with patients. A higher proportion of laboratories receive all data elements more than half of the time (i.e., 68 percent of laboratories receive the medical record number to 97 percent receive the date the specimen was submitted more than half of the time). Table 3 compares the differences between the perceptions of the laboratories and health care providers regarding data health care providers submit to laboratories.

Health care providers with HIV patients took an average of 12.5 days to report confirmed HIV cases to LHDs and a median of 95.5 percent of their HIV cases are reported to LHDs. ADAP physicians took the most time to report confirmed HIV cases to LHDs (15.0 days), followed by HIV test counselors and CMB physicians (10.3 and 7.6 days, respectively). On average, ADAP physicians have the most HIV patients with an average of over 242 patients and service up to 1,800 patients; the HIV test counselors and CMB physicians with patients handle an average of 18 and 14 patients, respectively. The ADAP physicians not only handle more HIV patients, but they also report higher levels of HIV cases to LHDs (85.4 percent), while HIV test counselors and CMB physicians report 51.6 percent and 42.7 percent of their confirmed HIV cases to LHDs.

Thirty-one of the 74 health care providers with HIV patients (41.9 percent) have established a cross-reference system. The top reason given by the 30 health care providers with HIV patients that lack a cross-reference system was the lack of resources such as time, personnel, and equipment; the remaining 13 health care providers did not respond.

Reporting Practices Among Laboratories

Of the 119 laboratory questionnaires returned, 97 (81.5 percent) have reported all confirmed HIV test results to LHDs since July 1, 2002. The reporting laboratories submit an

average of 83.3 percent of their confirmed HIV test results to LHDs and take an average of 3.6 days to send confirmed test results to LHD. Approximately 70 percent of reporting laboratories do not send confirmed HIV tests to LHDs electronically, but 90 percent of those that report electronically use the state recommended format.

Between 85-94 percent of laboratories submit all data elements, except soundex, more than half of the time to health care providers. Health care providers claim to receive the data elements less often than what the laboratories report; 39 percent of health care providers report receiving the soundex more than half of the time, but 82 percent of health care providers report receiving the results of the test performed more than half of the time. Table 4 summarizes the results about data from laboratories to health care providers according to laboratories and health care providers.

LHDs and laboratories agree laboratories generally send all data elements more than half of the time. Data elements are submitted by as little as 60 percent (Clinical Laboratory Improvement Amendments [CLIA] number) to as much as 95 percent (name of the test performed) of the laboratories most of the time, while as little as 29 percent (CLIA number) to as much as 92 percent (name of laboratory) of LHDs report receiving such data most of the time. The proportion of LHDs that report receiving the facility's address and phone number (66 percent and 61 percent, respectively) is lower than the proportion of laboratories that report supplying the same information (86 percent and 79 percent, respectively). Laboratories followed up with health care providers 65.6 percent of the time incomplete information for HIV specimen testing was submitted. Table 5 summarizes the results of data from laboratories according to laboratories and LHDs.

Reporting Practices Among LHDs

Over 68 percent of LHDs practice mostly active to all active surveillance with respect to HIV case reporting by health care providers. Use of active surveillance collects a higher percentage of data elements more than half of the time, whereas passive surveillance does not yield consistent data element collection. For example, the last four digits of the SSN was collected more than half of the time by 61 percent of LHDs on active surveillance reports, while 21 percent of LHDs receive it more than half of the time on passive surveillance reports.

Soundex also appeared more often on active surveillance reports than passive surveillance reports (61 percent most of the time compared to 26 percent most of the time). Table 6 compares the results of passive and active surveillance data collection.

Per LHD, an average of 404 HIV cases have been obtained through active surveillance since July 1, 2002, and an average of 85 HIV cases have been collected through passive surveillance. LHDs have reported 60.1 percent of their total HIV cases to OA. The 26 LHDs that practice mostly active to all active surveillance take an average of 24.3 days to submit completed HIV/AIDS Confidential Case Report forms to OA (range: 4-45 days). The average reporting time for those practicing mostly to all passive surveillance is 18.7 days (range: 0-60 days).

Satisfaction With Other Reporting Entities

The three reporting agencies are generally satisfied to very satisfied with one another. Over 72 percent of laboratories are satisfied with LHDs and 82 percent of LHDs are satisfied with laboratories. Mutual satisfaction between the laboratories and health care providers is evident with 73.1 percent of laboratories and 57.3 percent of health care providers being satisfied with their respective reporting partner. However, LHDs are evenly split between being satisfied and unsatisfied with health care providers (47 percent each). Reporting health care providers had a higher level of satisfaction with LHDs than those that do not report (80.9 percent versus 38.3 percent).

Reasons for not Reporting

There are apparent misconceptions between the three reporting agencies regarding reasons for not reporting. Half of the responding LHDs believe there are health care providers that are not reporting confirmed HIV (non-AIDS) cases. Non-reporting health care providers attribute the lack of HIV patients under their care and the lack of confirmed HIV test results from laboratories as primary reasons. Eight of the 94 non-reporting health care providers (8.5 percent) provided an invalid reason for not reporting. When asked the main reason health care providers do not report, LHDs indicated a lack of resources, such as time, personnel, and equipment and other specified reasons hinder the reporting process by health care providers. The other specified

reasons suggest health care providers do not see HIV reporting as a high priority, disagree with the mandates, and have general confusion of who and what has been reported. Table 7 summarizes the reasons given by LHDs and health care providers.

Two of the 38 responding LHDs suspect there are laboratories that are not reporting confirmed HIV test results to them. When asked for the main reason laboratories are not reporting, the lack of resources and other specified reasons were the main reasons given by LHDs. Specified reasons included confusion about which laboratories report, unclear reporting protocols, and HIV testing outside of the county. The lack of specimens for HIV testing and the fact they are reference laboratories are other reasons why LHDs suspect laboratories are not reporting. However, non-reporting laboratories cite the lack of confirmed HIV test results as their main reason for not reporting. Three of the 18 non-reporting laboratories (16.7 percent) provided invalid reasons for not reporting. For example, a laboratory stated that they did not need to report to the LHD because health care providers report to the LHD. Table 8 summarizes the reasons given by the laboratories and LHDs.

Training and Training Needs

Health care providers and laboratories received most of their training from LHDs and OA. The majority of laboratories (48.7 percent) received training from LHDs. Fifty-four (37.2 percent) health care providers did not receive any training. In regards to training needs, about 45 percent of laboratories (53 laboratories), and 53.1 percent of health care providers (77 health care providers) will not need any further assistance in HIV reporting. Among LHDs, 17 (46 percent) requested help with computer software and hardware needs. Another 14 (37.8 percent) LHDs need assistance in automating the matching process. The laboratories' top problem is electronically reporting confirmed HIV test results to LHDs. The development of a cross-reference system for all HIV patients was a primary concern for health care providers seeking assistance.

DISCUSSION

Overall, laboratories are reporting HIV cases more often than health care providers with HIV patients (81.5 percent versus 56.8 percent). Seventy percent of laboratories do not report

electronically; however, 90 percent of laboratories that do report electronically use the state recommended format. A reporting gap is present in that 43 percent of the health care providers with HIV patients do not report. Laboratories also report to LHDs faster (an average of 3.6 days) than health care providers, who take an average 12.5 days to report. Based on these averages, laboratories meet the seven-day reporting requirement specified in the HIV reporting regulations but health care providers do not. ADAP physicians particularly struggled to meet the reporting time requirements with an average reporting time of 15 days, but they also handle larger HIV caseloads.

Laboratories generally include all data elements most of the time when submitting information to LHDs and health care providers. However, health care providers claim to report data elements more often than what LHDs report receiving from health care providers on the case report forms. Laboratories are satisfied with the other two entities and also received high satisfaction ratings from LHDs and health care providers regarding their HIV reporting practices. Mutual satisfaction is present between health care providers and laboratories, but half of LHDs are unsatisfied with health care providers. Laboratories' reliability to report HIV tests compensates for the health care providers' reporting gap, highlighting the importance of the dual reporting system.

Laboratories and LHDs slightly differ in reasons given for the lack of reporting by laboratories. Laboratories cite the lack of confirmed HIV test results as the main reason they do not report, while LHDs believe the lack of resources such as time, personnel, and equipment is the main reason for not reporting. LHDs and health care providers also disagree on the main reasons health care providers do not report HIV cases. Health care providers claim a lack of HIV patients under their care and the lack of confirmed HIV test results from laboratories are the main reasons for not reporting, while LHDs suspect lack of resources such as time, personnel, and equipment and other specified reasons are the main problems.

Over two-thirds of LHDs receive reports from health care providers through active surveillance. This type of surveillance consistently collects more complete information than passive surveillance and yields a larger number of reported HIV cases (404 versus 85). Completed HIV/AIDS Confidential Case Report forms received through both types of

surveillance are forwarded to OA under the time reporting limit of 45 days, although active reports on average take longer than passive reports (24.3 days versus 18.7 days).

There were a few limitations to this study. The low response rate of 26.6 percent resulted in a total of 447 participants with approximately half of the health care provider participants having HIV patients under their care. So, the actual number of participants that were used in data analyses in regards to reporting practices was 46.8 percent (209/447), which is less than half of the small survey size. As a result, it is difficult to generalize the results of this survey to all health care providers, laboratories, and LHDs. Many of the returned survey packets were the result of an outdated mailing list. In addition, all of the responses were self-reported. There is no way to independently verify the validity of an individual's responses. All LHDs and laboratories that do HIV confirmatory testing were included in this survey, but only a sample of health care providers were included. Given available resources, it was difficult to target health care providers for whom the survey was applicable (namely, providers with HIV patients under their care) without biasing the sample toward those known to report HIV cases. As a result, many respondents in the survey did not have HIV patients and their responses may not reflect the reporting practices of those that do.

Increased compliance with the HIV reporting regulations continues to be a top priority. OA can improve upon the weaknesses exposed in the survey by meeting training needs identified by the three reporting entities. The reporting gap from health care providers may be improved through more overall training as 37.2 percent had not received any training. Training that addresses their main concern, cross-reference system development, is important since almost half of reporting health care providers lack such a system. Laboratories identified the need for assistance in electronically reporting confirmed HIV test results since 70 percent do not report electronically. LHDs requested assistance with automated matching and computer needs.

APPENDIX

Table 2. Reported Frequency of Submission from Health Care Providers to LHDs by Data Element.

DATA ELEMENT	HEALTH CARE PROVIDERS (n=74)		LHDs (n=38)	
	N	%	N	%
Soundex				
Less than half of the time	13	18	21	55
Half of the time	0	0	2	5
More than half of the time	27	36	10	26
Don't know/Not sure	19	26	2	5
Did not answer	15	20	3	8
Month of birth				
Less than half of the time	7	9	8	21
Half of the time	0	0	0	0
More than half of the time	41	55	24	63
Don't know/Not sure	12	16	2	5
Did not answer	14	19	4	11
Day of birth				
Less than half of the time	7	9	8	21
Half of the time	0	0	0	0
More than half of the time	41	55	24	63
Don't know/Not sure	12	16	2	5
Did not answer	14	19	4	11
Year of birth				
Less than half of the time	7	9	8	21
Half of the time	0	0	0	0
More than half of the time	41	55	24	63
Don't know/Not sure	12	16	2	5
Did not answer	14	19	4	11
Gender				
Less than half of the time	7	9	8	21
Half of the time	0	0	1	3
More than half of the time	42	57	23	61
Don't know/Not sure	11	15	2	5
Did not answer	14	19	4	11
Last four digits of SSN				
Less than half of the time	14	19	18	47
Half of the time	2	3	7	18
More than half of the time	29	39	8	21
Don't know/Not sure	13	18	2	5
Did not answer	16	22	3	8
Race/ethnicity				
Less than half of the time	12	16	17	45
Half of the time	1	1	6	16
More than half of the time	33	45	9	24
Don't know/Not sure	12	16	2	5
Did not answer	16	22	4	11

Table 2. Reported Frequency of Submission from Health Care Providers to LHDs by Data Element (cont.).

DATA ELEMENT	HEALTH CARE PROVIDERS (n=74)		LHDs (n=38)	
	N	%	N	%
Exposure/risk information				
Less than half of the time	11	15	23	61
Half of the time	1	1	5	13
More than half of the time	35	47	4	11
Don't know/Not sure	11	15	2	5
Did not answer	16	22	4	11
City of residence				
Less than half of the time	11	15	10	26
Half of the time	1	1	5	13
More than half of the time	36	49	17	45
Don't know/Not sure	12	16	2	5
Did not answer	14	19	4	11
County of residence				
Less than half of the time	9	12	11	29
Half of the time	1	1	6	16
More than half of the time	39	53	15	39
Don't know/Not sure	11	15	2	5
Did not answer	14	19	4	11
Zip Code				
Less than half of the time	9	12	13	34
Half of the time	2	3	3	8
More than half of the time	37	50	16	42
Don't know/Not sure	12	16	2	5
Did not answer	14	19	4	11
Date of death (if applicable)				
Less than half of the time	11	15	22	58
Half of the time	1	1	1	3
More than half of the time	27	36	5	13
Don't know/Not sure	18	24	6	16
Did not answer	17	23	4	11
Medical record number				
Less than half of the time	25	34	27	71
Half of the time	1	1	1	3
More than half of the time	18	24	4	11
Don't know/Not sure	14	19	2	5
Did not answer	16	22	4	11
CT# (If applicable)				
Less than half of the time	N/A		20	53
Half of the time	N/A		2	5
More than half of the time	N/A		3	8
Don't know/Not sure	N/A		4	11
Did not answer	N/A		9	24

Table 2. Reported Frequency of Submission from Health Care Providers to LHDs by Data Element (cont.).

DATA ELEMENT	HEALTH CARE PROVIDERS (n=74)		LHDs (n=38)	
	N	%	N	%
Documented lab information				
Less than half of the time	10	14	17	45
Half of the time	0	0	6	16
More than half of the time	37	50	9	24
Don't know/Not sure	13	18	2	5
Did not answer	14	19	4	11
Name of provider				
Less than half of the time	8	11	9	24
Half of the time	1	1	0	0
More than half of the time	40	54	23	61
Don't know/Not sure	11	15	2	5
Did not answer	14	19	4	11
Name of facility				
Less than half of the time	7	9	8	21
Half of the time	2	3	1	3
More than half of the time	40	54	23	61
Don't know/Not sure	11	15	2	5
Did not answer	14	19	4	11
Address of provider/facility				
Less than half of the time	7	9	10	26
Half of the time	2	3	2	5
More than half of the time	40	54	20	53
Don't know/Not sure	11	15	2	5
Did not answer	14	19	4	11
Phone number of provider/facility				
Less than half of the time	8	11	10	26
Half of the time	2	3	3	8
More than half of the time	39	53	19	50
Don't know/Not sure	11	15	2	5
Did not answer	14	19	4	11

COMPLIANCE WITH CALIFORNIA'S NON-NAME HIV REPORTING SYSTEM: A SURVEY OF HEALTH CARE PROVIDERS,
LABORATORIES, AND LOCAL HEALTH DEPARTMENTS

Table 3. Reported Frequency of Submission from Health Care Providers to Laboratories by Data Element.

DATA ELEMENT	HEALTH CARE PROVIDERS WITH PATIENTS (n=74)		HEALTH CARE PROVIDERS WITHOUT PATIENTS (n=46)		LABORATORIES (N=97)	
	N	%	N	%	N	%
Last name						
Less than half of the time	14	19	10	22	8	8
Half of the time	1	1	0	0	4	4
More than half of the time	51	69	24	52	84	87
Don't know/Not sure	1	1	2	4	0	0
Did not answer	7	9	10	22	1	1
Month of birth						
Less than half of the time	8	11	8	17	6	6
Half of the time	1	1	0	0	4	4
More than half of the time	56	76	26	57	86	89
Don't know/Not sure	2	3	2	4	0	0
Did not answer	7	9	10	22	1	1
Day of birth						
Less than half of the time	8	11	8	17	6	6
Half of the time	1	1	0	0	4	4
More than half of the time	56	76	26	57	86	89
Don't know/Not sure	2	3	2	4	0	0
Did not answer	7	9	10	22	1	1
Year of birth						
Less than half of the time	7	9	7	15	6	6
Half of the time	1	1	1	2	4	4
More than half of the time	57	77	25	54	86	89
Don't know/Not sure	2	3	3	7	0	0
Did not answer	7	9	10	22	1	1
Gender						
Less than half of the time	9	12	7	15	5	5
Half of the time	3	4	1	2	2	2
More than half of the time	49	66	24	52	88	91
Don't know/Not sure	3	4	3	7	0	0
Did not answer	10	14	11	24	2	2
Medical record number/Inmate ID number/Other patient ID number						
Less than half of the time	27	36	13	28	26	27
Half of the time	2	3	0	0	2	2
More than half of the time	30	41	18	39	66	68
Don't know/Not sure	7	9	5	11	1	1
Did not answer	8	11	10	22	2	2
Date specimen was collected						
Less than half of the time	6	8	5	11	0	0
Half of the time	1	1	0	0	2	2
More than half of the time	58	78	29	63	94	97
Don't know/Not sure	1	1	2	4	0	0
Did not answer	8	11	10	22	1	1

Table 3. Reported Frequency of Submission from Health Care Providers to Laboratories by Data Element (cont.).

DATA ELEMENT	HEALTH CARE PROVIDERS WITH PATIENTS (n=74)		HEALTH CARE PROVIDERS WITHOUT PATIENTS (n=46)		LABORATORIES (N=97)	
	N	%	N	%	N	%
Name of provider						
Less than half of the time	6	8	5	11	2	2
Half of the time	1	1	0	0	2	2
More than half of the time	60	81	27	59	90	93
Don't know/Not sure	1	1	3	7	1	1
Did not answer	6	8	11	24	2	2
Address of provider/facility						
Less than half of the time	7	9	5	11	10	10
Half of the time	1	1	1	2	4	4
More than half of the time	58	78	27	59	79	81
Don't know/Not sure	2	3	2	4	1	1
Did not answer	6	8	11	24	3	3
Phone number of provider/facility						
Less than half of the time	10	14	7	15	14	14
Half of the time	1	1	0	0	4	4
More than half of the time	53	72	26	57	75	77
Don't know/Not sure	3	4	2	4	1	1
Did not answer	7	9	11	24	3	3

Table 4. Reported Frequency of Submission from Laboratories to Health Care Providers by Data Element.

DATA ELEMENT	HEALTH CARE PROVIDERS (n=74)		LABORATORIES (N=97)	
	N	%	N	%
Soundex code				
Less than half of the time	15	20	21	22
Half of the time	0	0	1	1
More than half of the time	29	39	65	67
Don't know/Not sure	24	32	2	2
Did not answer	6	8	8	8
Month of birth				
Less than half of the time	6	8	5	5
Half of the time	1	1	2	2
More than half of the time	52	70	83	86
Don't know/Not sure	9	12	2	2
Did not answer	6	8	5	5
Day of birth				
Less than half of the time	6	8	5	5
Half of the time	1	1	2	2
More than half of the time	52	70	82	85
Don't know/Not sure	9	12	2	2
Did not answer	6	8	6	6
Year of birth				
Less than half of the time	7	9	5	5
Half of the time	1	1	2	2
More than half of the time	51	69	82	85
Don't know/Not sure	9	12	2	2
Did not answer	6	8	6	6
Gender				
Less than half of the time	8	11	3	3
Half of the time	0	0	1	1
More than half of the time	50	68	87	90
Don't know/Not sure	9	12	1	1
Did not answer	7	9	5	5
Date specimen was tested				
Less than half of the time	4	5	5	5
Half of the time	0	0	1	1
More than half of the time	59	80	87	90
Don't know/Not sure	4	5	1	1
Did not answer	7	9	3	3

Table 4. Reported Frequency of Submission from Laboratories to Health Care Providers by Data Element (cont.).

DATA ELEMENT	HEALTH CARE PROVIDERS (n=74)		LABORATORIES (N=97)	
	N	%	N	%
Accession number/Laboratory report number				
Less than half of the time	6	8	3	3
Half of the time	0	0	0	0
More than half of the time	56	76	90	93
Don't know/Not sure	7	9	1	1
Did not answer	5	7	3	3
Name of the test performed				
Less than half of the time	5	7	2	2
Half of the time	0	0	0	0
More than half of the time	59	80	91	94
Don't know/Not sure	4	5	1	1
Did not answer	6	8	3	3
Results of the test performed				
Less than half of the time	4	5	2	2
Half of the time	0	0	0	0
More than half of the time	61	82	91	94
Don't know/Not sure	4	5	1	1
Did not answer	5	7	3	3
Name of laboratory				
Less than half of the time	5	7	2	2
Half of the time	0	0	0	0
More than half of the time	59	80	91	94
Don't know/Not sure	4	5	1	1
Did not answer	6	8	3	3
Address of laboratory				
Less than half of the time	5	7	2	2
Half of the time	0	0	0	0
More than half of the time	56	76	91	94
Don't know/Not sure	7	9	1	1
Did not answer	6	8	3	3
Phone number of laboratory				
Less than half of the time	10	14	5	5
Half of the time	0	0	0	0
More than half of the time	50	68	87	90
Don't know/Not sure	8	11	2	2
Did not answer	6	8	3	3

Table 5. Reported Frequency of Submission from Laboratories to LHDs by Data Element.

DATA ELEMENT	LABORATORIES (N=97)		LHDs (n=38)	
	N	%	N	%
Soundex				
Less than half of the time	6	6	3	8
Half of the time	0	0	0	0
More than half of the time	84	87	34	89
Don't know/Not sure	4	4	1	3
Did not answer	3	3	0	0
Month of birth				
Less than half of the time	3	3	2	5
Half of the time	0	0	2	5
More than half of the time	87	90	33	87
Don't know/Not sure	2	2	1	3
Did not answer	5	5	0	0
Day of birth				
Less than half of the time	4	4	2	5
Half of the time	0	0	2	5
More than half of the time	86	89	33	87
Don't know/Not sure	2	2	1	3
Did not answer	5	5	0	0
Year of birth				
Less than half of the time	3	3	2	5
Half of the time	0	0	2	5
More than half of the time	87	90	33	87
Don't know/Not sure	2	2	1	3
Did not answer	5	5	0	0
Gender				
Less than half of the time	2	2	3	8
Half of the time	0	0	0	0
More than half of the time	88	91	34	89
Don't know/Not sure	2	2	1	3
Did not answer	5	5	0	0
Date specimen was tested				
Less than half of the time	3	3	2	5
Half of the time	0	0	0	0
More than half of the time	89	92	35	92
Don't know/Not sure	2	2	1	3
Did not answer	3	3	0	0

Table 5. Reported Frequency of Submission from Laboratories to LHDs by Data Element (cont.).

DATA ELEMENT	LABORATORIES (N=97)		LHDs (n=38)	
	N	%	N	%
Accession number/Laboratory report number				
Less than half of the time	7	7	2	5
Half of the time	0	0	1	3
More than half of the time	84	87	34	89
Don't know/Not sure	2	2	1	3
Did not answer	4	4	0	0
Name of the test performed				
Less than half of the time	0	0	3	8
Half of the time	0	0	0	0
More than half of the time	92	95	34	89
Don't know/Not sure	2	2	1	3
Did not answer	3	3	0	0
Results of the test performed including units				
Less than half of the time	1	1	2	5
Half of the time	0	0	1	3
More than half of the time	91	94	34	89
Don't know/Not sure	2	2	1	3
Did not answer	3	3	0	0
CLIA number				
Less than half of the time	25	26	5	13
Half of the time	0	0	1	3
More than half of the time	58	60	11	29
Don't know/Not sure	9	9	20	53
Did not answer	5	5	1	3
Name of laboratory				
Less than half of the time	0	0	2	5
Half of the time	0	0	0	0
More than half of the time	91	94	35	92
Don't know/Not sure	3	3	1	3
Did not answer	3	3	0	0
Address of laboratory				
Less than half of the time	1	1	2	5
Half of the time	0	0	0	0
More than half of the time	90	93	34	89
Don't know/Not sure	3	3	2	5
Did not answer	3	3	0	0

Table 5. Reported Frequency of Submission from Laboratories to LHDs by Data Element (cont.).

DATA ELEMENT	LABORATORIES (N=97)		LHDs (n=38)	
	N	%	N	%
Phone number of laboratory				
Less than half of the time	2	2	2	5
Half of the time	0	0	2	5
More than half of the time	87	90	33	87
Don't know/Not sure	3	3	1	3
Did not answer	5	5	0	0
Name of provider				
Less than half of the time	3	3	4	11
Half of the time	0	0	1	3
More than half of the time	88	91	32	84
Don't know/Not sure	3	3	1	3
Did not answer	3	3	0	0
Address of provider/facility				
Less than half of the time	7	7	9	24
Half of the time	0	0	3	8
More than half of the time	83	86	25	66
Don't know/Not sure	3	3	1	3
Did not answer	4	4	0	0
Phone number of provider/facility				
Less than half of the time	12	12	11	29
Half of the time	1	1	3	8
More than half of the time	77	79	23	61
Don't know/Not sure	3	3	1	3
Did not answer	4	4	0	0

Table 6. Completeness of Reporting to LHDs by Surveillance Type of Report.

DATA ELEMENT	ACTIVE SURVEILLANCE (N=38)		PASSIVE SURVEILLANCE (N=38)	
	N	%	N	%
Soundex				
Less than half of the time	10	26	21	55
Half of the time	1	3	2	5
More than half of the time	23	61	10	26
Don't know/Not sure	0	0	2	5
Did not answer	4	11	3	8
Month of birth				
Less than half of the time	3	8	8	21
Half of the time	0	0	0	0
More than half of the time	31	82	24	63
Don't know/Not sure	0	0	2	5
Did not answer	4	11	4	11
Day of birth				
Less than half of the time	3	8	8	21
Half of the time	0	0	0	0
More than half of the time	31	82	24	63
Don't know/Not sure	0	0	2	5
Did not answer	4	11	4	11
Year of birth				
Less than half of the time	3	8	8	21
Half of the time	0	0	0	0
More than half of the time	31	82	24	63
Don't know/Not sure	0	0	2	5
Did not answer	4	11	4	11
Gender				
Less than half of the time	3	8	8	21
Half of the time	0	0	1	3
More than half of the time	31	82	23	61
Don't know/Not sure	0	0	2	5
Did not answer	4	11	4	11
Last four digits of SSN				
Less than half of the time	7	18	18	47
Half of the time	3	8	7	18
More than half of the time	23	61	8	21
Don't know/Not sure	0	0	2	5
Did not answer	5	13	3	8

Table 6. Completeness of Reporting to LHDs by Surveillance Type of Report (cont.).

DATA ELEMENT	ACTIVE SURVEILLANCE (N=38)		PASSIVE SURVEILLANCE (N=38)	
	N	%	N	%
Race/ethnicity				
Less than half of the time	6	16	17	45
Half of the time	1	3	6	16
More than half of the time	27	71	9	24
Don't know/Not sure	0	0	2	5
Did not answer	4	11	4	11
Exposure/risk information				
Less than half of the time	13	34	23	61
Half of the time	3	8	5	13
More than half of the time	17	45	4	11
Don't know/Not sure	0	0	2	5
Did not answer	5	13	4	11
City of residence				
Less than half of the time	4	11	10	26
Half of the time	2	5	5	13
More than half of the time	28	74	17	45
Don't know/Not sure	0	0	2	5
Did not answer	4	11	4	11
County of residence				
Less than half of the time	4	11	11	29
Half of the time	2	5	6	16
More than half of the time	28	74	15	39
Don't know/Not sure	0	0	2	5
Did not answer	4	11	4	11
Zip Code				
Less than half of the time	5	13	13	34
Half of the time	1	3	3	8
More than half of the time	28	74	16	42
Don't know/Not sure	0	0	2	5
Did not answer	4	11	4	11
Date of death (if applicable)				
Less than half of the time	9	24	22	58
Half of the time	1	3	1	3
More than half of the time	18	47	5	13
Don't know/Not sure	4	11	6	16
Did not answer	6	16	4	11

Table 6. Completeness of Reporting to LHDs by Surveillance Type of Report (cont.).

DATA ELEMENT	ACTIVE SURVEILLANCE (N=38)		PASSIVE SURVEILLANCE (N=38)	
	N	%	N	%
Medical record number				
Less than half of the time	16	42	27	71
Half of the time	2	5	1	3
More than half of the time	16	42	4	11
Don't know/Not sure	0	0	2	5
Did not answer	4	11	4	11
CT# (If applicable)				
Less than half of the time	17	45	20	53
Half of the time	0	0	2	5
More than half of the time	8	21	3	8
Don't know/Not sure	4	11	4	11
Did not answer	9	24	9	24
Documented lab information				
Less than half of the time	6	16	17	45
Half of the time	5	13	6	16
More than half of the time	23	61	9	24
Don't know/Not sure	0	0	2	5
Did not answer	4	11	4	11
Name of provider				
Less than half of the time	3	8	9	24
Half of the time	1	3	0	0
More than half of the time	30	79	23	61
Don't know/Not sure	0	0	2	5
Did not answer	4	11	4	11
Name of facility				
Less than half of the time	3	8	8	21
Half of the time	0	0	1	3
More than half of the time	31	82	23	61
Don't know/Not sure	0	0	2	5
Did not answer	4	11	4	11
Address of provider/facility				
Less than half of the time	4	11	10	26
Half of the time	2	5	2	5
More than half of the time	28	74	20	53
Don't know/Not sure	0	0	2	5
Did not answer	4	11	4	11

Table 6. Completeness of Reporting to LHDs by Surveillance Type of Report (cont.).

DATA ELEMENT	ACTIVE SURVEILLANCE (N=38)		PASSIVE SURVEILLANCE (N=38)	
	N	%	N	%
Phone number of provider/facility				
Less than half of the time	4	11	10	26
Half of the time	2	5	3	8
More than half of the time	28	74	19	50
Don't know/Not sure	0	0	2	5
Did not answer	4	11	4	11

Table 7. Reasons Given by Health Care Providers and LHDs For Lack of Reporting by Health Care Providers.

REASON	ADAP PHYSICIANS (n=7)		CMB PHYSICIANS (n=64)		HIV TEST COUNSELORS (n=22)		LHD (n=38)	
	N	%	N	%	N	%	N	%
Lack of HIV (non-AIDS) patients/clients								
Yes	1	14	37	58	8	36	13	34
No	6	86	27	42	11	50	25	66
Did Not Answer	0	0	0	0	3	14	0	0
Lack of confirmed HIV test results								
Yes	2	29	26	41	6	27	2	5
No	5	71	38	59	13	59	36	95
Did Not Answer	0	0	0	0	3	14	0	0
Don't know HIV (non-AIDS) cases reportable								
Yes	0	0	1	2	0	0	11	29
No	7	100	63	98	19	86	27	71
Did Not Answer	0	0	0	0	3	14	0	0
Confidentiality and/or HIPAA regulations concerns								
Yes	0	0	1	2	0	0	20	53
No	7	100	63	98	19	86	18	47
Did Not Answer	0	0	0	0	3	14	0	0
Alternative or anonymous HIV testing site								
Yes	0	0	0	0	5	23	5	13
No	7	100	64	100	14	64	33	87
Did Not Answer	0	0	0	0	3	14	0	0
Blood banks or plasma centers								
Yes	0	0	0	0	0	0	3	8
No	7	100	64	100	19	86	35	92
Did Not Answer	0	0	0	0	3	14	0	0
Patients/clients in "blinded and/or unlinked seroprevalence studies"								
Yes	0	0	0	0	0	0	2	5
No	7	100	64	100	19	86	36	95
Did Not Answer	0	0	0	0	3	14	0	0
Lack of resources (time, personnel, equipment)								
Yes	N/A		N/A		N/A		23	61
No	N/A		N/A		N/A		15	39
Did Not Answer	N/A		N/A		N/A		0	0
Other								
Yes	4	57	15	23	3	14	16	42
No	3	43	49	77	16	73	22	58
Did Not Answer	0	0	0	0	3	14	0	0

Table 8. Reasons Given by Laboratories and LHDs for Lack of Reporting by Laboratories.

REASON	LABORATORIES (n=18)		LHDs (n=38)	
	N	%	N	%
Lack of specimens				
Yes	1	6	7	18
No	17	94	17	45
Did Not Answer	0	0	14	37
Don't know confirmed HIV tests are reportable				
Yes	1	6	3	8
No	17	94	21	55
Did Not Answer	0	0	14	37
Lack of confirmed HIV test results				
Yes	9	50	3	8
No	8	44	21	55
Did Not Answer	1	6	14	37
Confidentiality and/or HIPAA regulations concerns				
Yes	0	0	5	13
No	17	94	19	50
Did Not Answer	1	6	14	37
Reference laboratory				
Yes	1	6	6	16
No	16	89	18	47
Did Not Answer	1	6	14	37
Specimens from blood banks or plasma centers				
Yes	1	6	0	0
No	16	89	24	63
Did Not Answer	1	6	14	37
Specimens from alternative/anonymous HIV testing sites				
Yes	0	0	2	5
No	17	94	22	58
Did Not Answer	1	6	14	37
Specimens from "blinded and/or unlinked seroprevalence studies"				
Yes	0	0	0	0
No	17	94	24	63
Did Not Answer	1	6	14	37
Lack of resources (time, personnel, equipment)				
Yes	N/A		7	18
No	N/A		17	45
Did Not Answer	N/A		14	37
Other				
Yes	7	39	8	21
No	10	56	16	42
Did Not Answer	1	6	14	37

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